

SCLERODERMA DEFIANCE: A PRACTICAL, EDUCATIONAL AND FREE GUIDE FOR
SELF-MANAGEMENT OF SCLERODERMA

by

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Abstract

Scleroderma is a rare and incurable autoimmune disease characterized by overproduction of collagen, which often leads to organ damage and sclerotic tissue. This health condition affects multiple organ systems and tissues, such as the skin and digestive system. In the United States, it is estimated that 300,000 people suffer from this disease. Being diagnosed with Scleroderma is life changing and often results in feelings of helplessness and depression. Although there is no cure for this disease at this time, those with Scleroderma can slow the disease progression or even achieve a state of remission. For many, the internet is one of the first resources used to gather information regarding a medical diagnosis and disease management. However, online resources for Scleroderma patients are scarce and information regarding lifestyle modification is virtually non-existent. Nutritional counseling with Registered Dietitians (RD) has been shown to improve health outcomes in Scleroderma patients. Unfortunately, people with Scleroderma are rarely referred to RDs for nutritional consultations, which are not covered by medical insurance. Sclerodermadefiance.com is a free, comprehensive, online resource. It is designed to provide information that will help patients to manage Scleroderma symptoms. The goal is to help Sclerodermadefiance.com users improve health and nutritional status by making this comprehensive online research available free of charge.

Scleroderma, more recently referred to as Systemic Sclerosis, is an incurable autoimmune disease of the connective tissues. This disease is estimated to affect 300,000 U.S. citizens. There are multiple forms of Scleroderma, each with its own degree of severity and set of signs and symptoms. The most common feature of this disease is over production of collagen and subsequent hardening of bodily tissues and organs (Scleroderma Foundation, n.d.). This hardening of tissues is driven by inflammation and oxidative stress experienced by the patient (Grygiel-Gorniak & Puszczewicz, 2014). The speed of disease progression can vary considerably from slow to rapid. The extent of progression also varies from case to case. Some patients suffer from systemic forms of the disease, while in others, the disease progression may be confined to a specific part of the body (Scleroderma Foundation, n.d.). In either case, being diagnosed with Scleroderma can be life changing, and I can attest to this being someone diagnosed with Diffuse Systemic Sclerosis. Living with this disease can be extremely challenging, especially when organ systems are compromised or when eating becomes difficult due to developing dysphagia, gastroparesis, or mal-absorptive issues. Serious progression of Scleroderma results in significant change to an individual's quality of life and potentially their life expectancy. While currently there is no cure, some patients can achieve a state of remission where disease progression halts, making disease management even more important.

An individual's health depends largely on adequate food intake and maintenance of healthy weight. Scleroderma sufferers frequently experience malnutrition due to disease progression in the gastro-intestinal (GI) tract. Medical Nutrition Therapy (MNT) provided by Registered Dietitians (RD) has been shown to improve health and alleviate malnutrition in cases of Scleroderma. Despite being of significant benefit, patients with Scleroderma are rarely referred to RD's for MNT. Even if they are referred, most patients must pay for their services without the

help of insurance (Doerfler et al., 2015). In addition, resources for management of Scleroderma symptoms that incorporate nutrition based strategies to improve health outcomes are scarce; further illustrating the need for this project.

The goal of this endeavor was to create a free, web-based resource for those suffering from Scleroderma in order to provide information that may help to improve Scleroderma Patients' quality of life. This is neither a purely research based project or purely creative endeavor, but rather, it is a mix of both. Completing this project required combining my technical knowledge of studying and surveying relevant scientific literature with my creative and practical abilities. I created Sclerodermadefiacne.com by turning research into strategies to be applied in daily life for management of Scleroderma. I also incorporated elements based on my own personal experience with this disease along with what I learned while creating this resource. Within this resource, one will find recommendations regarding a variety of topics including diet, lifestyle, supplementation, as well as other relevant material. In addition, recipes for foods and specific homemade cleaning and hygiene products have also been included. This resource is meant to provide the knowledge necessary for those with Scleroderma to make changes in their daily lives to manage symptoms and disease progression. I also hope this resource will help improve the mental outlook of individuals by providing them with an optimistic perspective regarding their disease prognosis.

As previously stated, this endeavor has added value to my college experience by combining my skills and using them in a way relevant to my discipline. Registered Dietitians fulfill many professional roles in society and being skilled in multiple areas, as well as creative and flexible generates more opportunities for success and positive impacts. Dietitians can be researchers, authors, political figures, teachers, chefs, community members and so much more. Over the past

four years, I have learned of the diverse roles of Dietitians and have personally set out to cultivate my skills in multiple areas, while still remaining true to my individual passions. I have learned to research, worked relentlessly to improve my writing abilities, and taught myself how to cook nearly anything. My cooking skills have gone far beyond just basic. I now know how to translate nutrition-related health recommendations into diet, recipes, and lifestyle choices. I have learned an immense amount but I felt creating a website would only further enhance my skillset, as well as diversify it.

Despite being in a technologically driven age, I have always lacked some interest in technology. When it comes to technology, I tend to learn the baseline in order to stay up to date but never pursue anything deeper, as it is not a priority in my life. I am a person that enjoys things such as cooking, artistic projects, and gardening. In all honesty, I try to avoid sitting behind computers, if I can. Creating a website was something I had never done or had ever even considered doing prior to this project. When I first got the idea for this project, I was imagining this resource more in the format of a book. However, I quickly realized a book would not suit my audience or make much sense with what I truly wanted to accomplish. I felt a book would limit the type of content I could create, while a website would allow for many possibilities.

Using a website has many benefits. The internet allows for easy access to information for people all over the world. It is also one of the first places people go to lookup information regarding a medical diagnosis. After reflecting on my own experience with this disease, I realized that a website would likely be the easiest and most effective way to reach my audience. Those diagnosed with Scleroderma, especially younger generations, will likely use the internet as a primary resource for understanding their diagnosis after leaving their doctor's office. Despite my lack of interest in technology, I decided it would be best to learn more about how to use it to

my advantage. In doing so, I have gained an important skill used by many RDs to promote healthy living through web-based platforms.

Creating a website for this project has allowed me to share diverse content. I have been able to incorporate educational information, images, helpful links, recipes and videos all in one resource. This simply cannot be done with a book. Another important consideration for choosing a website format is its ability to be changed and updated as frequently as needed. Updating a book is more of a process in comparison and can't be accomplished as easily. I can easily update the content of a website and provide more information as the scientific understanding of Scleroderma and its treatments evolve over time. A website also provides a platform for interaction between myself and others with Scleroderma. Visitors to Sclerodermadefiance.com are easily able to contact me. Based on questions and feedback from visitors I can change my website content to better suit their needs.

In choosing a website, I also considered the audience I am trying to reach. While a web-based resource does not highly limit an audience because it is so easily accessible, I feel certain individuals are more likely to use the internet than others. Namely, young individuals are skilled at navigating the internet because it is something they have grown up using. To a large degree, I am targeting young and middle-aged individuals as they are more likely to make lifestyle changes compared to an older population. Targeting younger individuals with health messages is also more likely to have a significant impact, simply due to age alone. As with any chronic disease, it is best to prevent progression early when better health outcomes are easier to achieve.

Creating a web-based resource was challenge for me but I now possess the necessary skills to do it again. Some of the most challenging aspects of this project were design and organization. I spent a considerable amount of time conceptualizing and imaging what I wanted to create. As

with any website, design is important for the user's experience. Organizing my thoughts, the website sections, and finding a suitable template to convey the information were some of the aspects I struggled with. I also spent a large portion of my time studying websites and how to create them. In addition to organizing the site itself, I also struggled with organizing my time for this project, despite planning. It was not always clear when and what I should have been doing at particular points during the website creation process. For example, early in the creation process I attempted to put content on my site but had not fully finished learning about the best way to do so. Once I realized my error, I would start again by filling my knowledge gaps. Similar instances such as this happened multiple times. I quickly had to figure out the proper order of operations for completing a project such as this one. While I may have struggled with many aspects of creating SclerodermaDefiance.com, including webhosting and support issues, I have successfully reached a point in which I feel comfortable creating well planned websites.

The resource I have created is not a research paper or a unique work of art, but it is true to my career path and personal development. This project represents some of my greatest personal accomplishments that I can now share with others in order to help those diagnosed with Scleroderma. I argue this project shows my growth as a student towards becoming an independent professional capable of recognizing needs, managing projects, and creating something valuable to others. With this project, I have achieved something I am proud of and I look forward to seeing the impact I believe it will have.

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